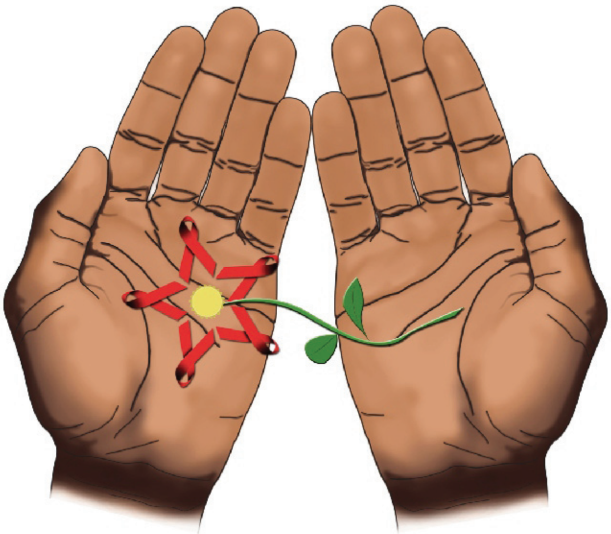
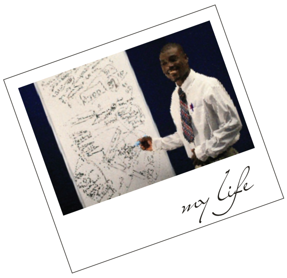
MODULE 9
Stigma & Discrimination

Facilitator's Booklet

MY LIFE





Positive Living Toolkit

“Hope is in Our Hands”

GHANAIANS AND AMERICANS IN PARTNERSHIP TO FIGHT HIV/AIDS
USAID FROM THE AMERICAN PEOPLE
GHANA AIDS COMMISSION
GHANA HEALTH SERVICE
Your Health-Our Concern

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TECHNICAL CONTENT MANUAL

Module 9
STIGMA & DISCRIMINATION

Objectives

- Know the connection between stigma and disclosure.
- Understand how stigma and discrimination affects you internally and also affects your life.

Time

- 45 minutes

Materials

- CD Player
- "My Life" CD (Disc 10) Track 1: Stigma, Discrimination and Your Life

Preparation

Listen to the CD and become familiar with the terms stigma and discrimination as well as resources to share with support group participants where they can seek information and assistance.

Facilitator

Tell participants the following:

Today will be discussing HIV/AIDS-related stigma and discrimination and how they affect our lives.

Ask participants the following:

What are some examples of HIV stigma and discrimination that you or someone you know has experienced?

Possible examples include:

- Isolation: Physical or social isolation from family and friends like kicked out of the house
- Violence: Physical, sexual, or verbal violence towards PWLHA and/or their family and friends
- Belittling, name-calling, blaming, labeling as "immoral" for having HIV
- Not being included in decisions related to the family or one's own health and well-being
- Being fired from your job

Facilitator

Ask participants:

What do you think are some of the causes of HIV stigma and discrimination?

Possible answers include:

- Lack of information and knowledge about HIV
- Misconceptions/ misunderstandings about how HIV is transmitted

- Fears of illness, contagion, and death
- Social inequalities and prejudices against certain groups of people: women, men who have sex with men, commercial sex workers, etc.

Facilitator
Tell Participants the following:
We will listen to Edna's story about stigma and discrimination. Remember you have already heard Edina's story in Module 3 - Positive Living
The story will be divided into three parts so we can discuss important points throughout the story.
The discussions will happen in small groups so everyone has a chance to talk.
At the end of the story, the main points will be reviewed.

1. Edna's Story Part One
When Edna was diagnosed as HIV positive about 8 years ago, she was shocked because she had been faithful to her husband for many years and the diagnosis meant that he had sex with other women while he was married to her. When she told her husband about the HIV test results he told her to leave, and he kept their two children. Then her family rejected her because they were afraid to get sick and also did not want anyone to know that Edna was HIV positive so they told her to leave.

Edna had no home, no family, no job, so she left the village and went to the city to get a job so she could feed herself. This was not easy, she was afraid and many nights she slept outside on the pavement. She was desperate and many times she wanted to die as she felt she did not matter to anyone she knew in her life. She also felt that God was punishing her for something she had done.

Edna says that she often saw herself fundamentally changed, in a matter of minutes. “I thought that I was marked, different from everyone else. I felt dirty, ashamed, and guilty (although I wasn't sure why I felt guilty, it just felt like an appropriate response). It is hard to convey the confused feelings about getting ready to die when I felt perfectly well. Feeling that overnight I had lost my right to a relationship, children, a job, to travel, to be happy everything had changed but nothing had changed... An HIV diagnosis is life changing people feel dirty, abnormal, frightened. The first challenge is to regain a sense of self-worth, dignity and to take back control over a life torn apart by HIV”[1]

PAUSE THE STORY.

Facilitator

Divide participants into small groups.
Ask groups to discuss the following questions:

How did stigma and discrimination affect Edna?
How did it make her feel?

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[1] From “HIV and Self-Stigma: Summary of Stigma-AIDS eForum discussion” Health & Development Network, 2004.

Possible Answers:
The following effects relate to the internalized stigma many people feel over the course of his/her life after learning their HIV positive status:

- Feelings of sadness, hatred to self and others, feelings of revenge and infecting others so that they can be like me
- Facilitator also brings out other effects such as:
- Depression, low self-esteem, even thoughts of suicide, which can lead to increased stress on the body; feelings of worthlessness or hopelessness (nothing to live for); feeling a lack of empowerment or not worthy of protecting oneself.
- Feeling dirty or unclean or inferior to others.
- Blaming oneself.
- Cutting off or eliminating interpersonal connections for fear of a loss of familial/social network support and/or physical or emotional segregation, i.e., cut off your family so you don't cause them shame or before they reject you.
- Denial of status and avoidance of practicing prevention efforts include:
  - Increased rates of risk behavior.
  - Fear losing partner.
  - Fear use of condoms will "disclose" your status.
- Cutting off family so you do not cause them shame.

Facilitator
Tell Participants the Following:

We will listen to the second part of Edna's story.

2. Edna's Story Part 2.

When Edna told her husband Kofi about the HIV test results she did not want to keep secrets with him. At first he did not believe her. She had to show him the test results from the health center. He then started to get upset and angry with her and blaming her for the results, Kofi did not want to listen to Edna's explanation and told her that he no longer wanted her in the house because the children could also get infected. Edna could not believe what she was hearing and did not want to leave her two children either. She thought that Kofi was going to help her and support her at this time. But, Kofi did not want her around him or the children. Edna was very upset and at some point, Kofi almost hit her and kicked her out of the room.

When her family found out about the trouble between Kofi and Edna, they also told her that she had to leave the village. They told Edna that the children were better of without her and they would help Kofi take care of them. Edna felt that all this was happening to her because she told the truth. She did not want to keep secrets from anyone. This was a very bad time in Edna's life. No one wanted to see her or be near her, she felt like monster and also felt that her family was ashamed of her and she needed to leave.

PAUSE THE STORY.

Facilitator
In the same groups participants discuss the following question:

What are the effects of external HIV stigma and discrimination? Listen to their responses, you can also write them down on a flip chart. Watch out for some of the participants to share their won testimonies relate to stigma and discrimination they went through. Encourage them to share their feelings and how they managed to cope with the situation

In addition tell participants the following:

Many people feel the following effects of external stigma:

- Thinking someone is dirty, unclean, or immoral because they are living w/ HIV.
- Blaming PLHIV for their disease.
- Calling them or thinking of them as inferior to you and others.
- Acts of violence against PLHIV.
- Isolating or separating PLHIV either physically, socially, or emotionally.
- Cutting off familial, economic, and social support networks for PLHIV.
- Firing someone living HIV from his/her job.
- Avoiding/Reluctance to seek testing for fear of a positive result.
- Insulting or gossiping about others (considering a person living with HIV as the "walking dead" or already dead, so they don't deserve love and respect).

Facilitator
Tell participants the following:

We will now listen to the third part of Edna's story.

2. Edna's Story Part 3.

One day Edna was desperate and hungry. She went to a local church to seek help. At first people there, did not want her to stay, but a kind woman gave her food and someone helped her get a job at a fish factory nearby. Edna was very grateful and thanked God for helping her to have the courage to go inside the church and ask for help. Over the next few months Edna began to think about her life. She needed to accept what was happening to her and she needed to learn to live with it because no one else could do that for her. She had to do it for herself. She also realized that there were many people living with HIV and AIDS that were being rejected by their families and their communities.

A few years later, Edna found out that her husband and one of her children had died from AIDS. She has now reconciled with her family. She strongly believes that she was determined to live. She had to accept herself first and then she could help herself and not feel alone any more. Edna has also started ART treatment now.

Facilitator
Bring the group back together to discuss this question:

What helped Edna to help herself?

Possible Answers:

- She found a resource that could help her the church or supportive persons
- She found someone who accepted her as an HIV positive person
- She disclosed her status and began to accept herself
- She changed her attitude
- She found a new purpose in her job

In addition find out from the group if there are those who have looked for other resources to support them and how they feel about it now. Encourage them to share as much as they can among themselves.

KEY POINTS:

Facilitator

Tell participants the following:

Remember that while there is a difference between stigma within yourself and stigma by others, remember that the way you see yourself may be different from how others see you,

- The way you see yourself may be shaped by others' perceptions, including their prejudices.
- You have the power to accept the positive.
- You have the power to reject or change the negative.
- Only you have the power to change, others can not change you.

Module 9: Stigma And Discrimination
Activity 2- Coping With Stigma And Discrimination

Objectives

- To identify strategies to recognize stigma and discrimination.
- To identify and practice ways to cope with stigma and discrimination.

Time

- 30 minutes

Materials

- CD player
- "My Life" CD (Disc 10) Track 2: Coping with Stigma and Discrimination

FACILITATOR
Health worker or NGO worker

Preparation

Listen to the CD and become familiar with the terms stigma and discrimination as well as resources to share with support group participants where they can seek information and assistance.

Facilitator

Tell participants the following:

Today will discuss the definition of stigma and discrimination and ways to cope with them especially if you are taking ARV.

Divide participants into small groups.

Have them discuss the following:

What is HIV Stigma and discrimination according to you?

Bring groups together and share their responses.

Possible Answers:

- Definition of HIV/AIDS related - stigma: "a process of devaluation of people either living with or associated with HIV and AIDS (UNAIDS, 2003). (Is this useful? Do you really think someone will come up with this answer?

- To believe someone is inferior, or not good, because they have HIV/AIDS. An example is the belief that PLHIV deserve what happened to them because they did something immoral or illegal.

- Definition of HIV/AIDS related discrimination (on tape): is the action that often times follows stigma (enacted stigma). It is defined as the "unfair and unjust treatment of an individual based on his or her real or perceived HIV status" or those associated with HIV (UNAIDS, 2003). Same comment this seems just a more complicated way to say what is said below.

- To treat or act unfairly or unkindly towards someone because you either think or you know they have HIV/AIDS. For example, when PLHIV lose their jobs or are refused treatment or treated unfairly by health care providers.

Facilitator
In same small groups ask participants the following:

What are the possible sources of HIV stigma and discrimination?

Bring groups together and share responses

Possible Answers:
- Lack of accurate information.
- People have misconceptions and misunderstandings about HIV and ways HIV is transmitted.
- People make assumptions based on these misconceptions and misinformation.

For example:
- If a woman does not have children or is not married, there must be something wrong with her, or she is sick.
- If someone has lost weight or maybe looks tired it must be HIV.
- That person has HIV, he/she must have done something to deserve it or he/she is a bad person.
- If I eat with someone with HIV I will get HIV too.

Facilitator
In same small groups ask participants:

Find out if there are some participants who have found themselves in these situations. Encourage them to share among themselves what they did to overcome these challenges?

What else can be done by other people if they found themselves in such situations?

Bring groups together and share responses.

Possible Responses:
- Challenge stigmatizing situations and cope with stigma by responding in a non - aggressive way.
- Do not make the stigmatizer defensive.
- Provide a strong response making the other person think.
    - Examples of strong responses:[2]

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[2] Adapted from ICRW Toolkit Module Moving to Action: Exercise 10: Page 25.

  - You are probably not aware that you are stigmatizing.
  - You only need to sleep with one person to get HIV.
  - All of us are at risk of getting HIV so there is no point stigmatizing others.
  - Anyone can get HIV, so put yourself in my shoes and think how you would feel.
  - The same thing could happen to you.
  - Don't point fingers at anyone. As you point one finger towards others, four fingers are pointing back towards you you are blaming yourself.
- Correct myths and perceptions about HIV.
- Take ARVs and adhere to treatment to stay healthy.
- Talk to friends or family about your experiences with stigma and discrimination.
- Provide support to your own friends and family who are living with HIV/AIDS.

Facilitator
Tell participants the following:

We will have a chance to practice responding to HIV Stigma and Discrimination in an effort to reduce and stop it.[3]

We will do some role plays.

Ask participants to form groups of 3 and select a role play from the following situations:

1. You are going to the market and you pass close to a vendor and the vendor moves back to let you go and tells you: I do not want to get sick, do not come closer. How do you respond?
2. You are at home and you hear your cousin say that she will not sit with you at the same table because she thinks you are evil. How do you respond?
3. You are talking to some friends and they say, "You have been talking a lot about AIDS and telling us to get tested. Does that mean you have AIDS? Have you been tested for AIDS?" How would you respond to your friends in this situation?

Ask the groups to practice their responses.

Bring groups together and share their responses.

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[3] Adapted from ICRW Toolkit Module G Treatment and Stigma: Exercise G2: Page 26.

Module 9: Stigma And Discrimination
Activity 3- Stigma, Discrimination And Your Health

Objectives
- Understand how stigma and discrimination affects your health (physical and emotional).
- Identify ways to improve your health.

Time
- 30 minutes

Materials
- CD player
- "My Life" CD (Disc 10) Track 3: Stigma, Discrimination and Your Health

Facilitator
Tell participants the following:

Today will be discussing HIV/AIDS-related stigma and discrimination and how they affect the health of PLHIV.

Ask participants in plenary:

What are some examples of HIV stigma and discrimination?

Possible examples include:
- Physical, sexual, or verbal violence towards PWLHA and/or their family and friends.
- Physical or social isolation from family and friends or kicked out of the house.
- Not included in decisions related to the family or one's own health and well-being.
- Belittling, name-calling, blaming, labeling as "immoral" for having HIV.
- Being fired from your job.

Facilitator

Ask participants

How can HIV stigma and discrimination affect a person who is HIV positive?

Possible Answers:

- Lowers self esteem
- Believe that they are going to die soon
- Increase stress level, which can negatively impact their immune system
- Worry and negative feelings
- Depression

- Isolation
- Stop eating and get sick
- Feel powerless and useless

Facilitator
Tell participants the following:

As we know, there is a connection between the mind and body. For example, many people believe physical health is affected by emotional health. Poor emotional health can result from experiences of stigma and discrimination.

Now, we will listen to the Story of Lucy.

Start the CD now:

Story of Lucy[4]

When Lucy's family learned of her HIV status, they advised her to find a house close to the public cemetery. "We do not have money to put into your funeral arrangements, let alone your husband's," they told her. At 23 and pregnant with her second child, Lucy was caring for her ailing husband and their five-year old son with proceeds from her vegetable kiosk. But when word got out that she and her husband were living with HIV, her customers stopped coming, because they feared catching HIV.

The situation took its toll on the young mother. Soon after her baby was born, Lucy weighed only 45 kg. Then two months later, Lucy's infant died from pneumonia. Her world tumbled down, and she wanted to give up living so badly. What stopped Lucy was the hope that she saw radiate every day from her five-year-old son. One day Lucy met Miriam, a church social worker. Lucy told her that she was very lonely and was looking for someone she could talk to about her situation. Miriam told Lucy about a support group for people living with HIV/AIDS that met frequently at the nearby church. When Lucy went to the support group for the first time, Miriam introduced her to the group members. Lucy decided to join the support group and also started following the nutrition program that they offered for PLHIV. She now has gained 10 kilos and her CD4 count has risen from 280 to 540. Lucy now can retain the food she eats and says that before she was always sickly and spent most of her time in bed. She explains that she sometimes falls sick, once in a while, but her life has taken a complete turn from last year. Lucy says she feels strong most days and does not worry all the time. Now she can take better care of her husband and her child. She is also grateful to have a group of people in her support group to take care of her. She never gave up hope that she could be strong again and help her family.

Facilitator
Ask participants the following

What were some examples of the effects HIV stigma and discrimination in Lucy's body and mind?

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[4] FHI Feeding the Body and Strengthening the Spirit..

Possible Answers:

Effects of stigma/discrimination on physical and emotional heath:

- Many believe there is a connection between the mind and body.
- Studies have shown that stress, worrying, prolonged grief, depression, low self-esteem, and negative thinking can impact the immune system and can weaken it.
- A weakened immune system leads to faster disease progression and/or poorer health outcomes.

Facilitator
Ask participants the following

What are some examples of Lucy's positive attitudes in her body and the mind?

Possible Answers:

- Positive thinking, support from loved ones, self-assertiveness, physical exercise, and reduced levels of stress and grief can have a positive impact the immune system and health outcomes.
- Additionally, those who have disclosed their HIV status at least to some of their loved ones, are generally better able to access to appropriate health care services and social support networks.
- Joining a support group can boost in immune system.
- Other actions that can boost the immune system include:
  - Continue to take the medication according to the doctor's orders.
  - Believing in that you can live positively with HIV.
  - Believing you have the right to be loved, respected, and to live life to its fullest.
  - Self-disclosure to trusted loved ones and talking about problems openly and honestly.
  - Life purpose and goals: research shows PLWHA who have remained healthy for long periods of time show that they have “reasons to live,” either for general purposes (“I want to enjoy my family and friends”) or specific purposes (“I want to watch my children grow up” or “I want to take a class next month”).
  - Self-assertiveness or sticking up for yourself and your self-interests (increase self-esteem).
  - Body care: nutrition, exercise, regular sleep, etc.

Facilitator
Ask participants to share their stories of stigma and discrimination and how that affected their physical and emotional health? Encourage to share how they feel now that they are part of a support group where there is care, respect and love from others.

KEY MESSAGES:

- Studies have shown that stress, worrying, prolonged grief, depression, low self-esteem, and negative thinking can impact the immune system and can weaken it.
- A weakened immune system leads to faster disease progression and/or poorer health outcomes. Research shows PLWHA who have remained healthy for long periods of time state that they have "reasons to live," either for general purposes ("I want to enjoy my family and friends") or specific purposes ("I want to watch my children grow up" or "I want to take a class next month") Having a life purpose and goals.
- Self-assertiveness or sticking up for yourself and your self-interests (increase self-esteem).
- Body care: nutrition, exercise, regular sleep, etc.

Module 9: Stigma And Discrimination
Activity 4- Health Worker-patient Role Play

Objectives
- To gain basic skills in communicating assertively with health workers regarding PLHIV stigma and discrimination issues.
- PLHIV can act as Queen Mothers when dealing with health providers by asking key questions to the health worker and by talking assertively to the health worker.

Time
- 45 minutes

Materials
- Health worker and patient character cards of Queen Mother/King
- ''My Life'' CD (Disc 10) Track 4: Health Worker-Patient Role Play
- CD Player

Facilitator

Health worker or NGO worker

Preparation
- Make sure you have all of the above-listed materials with you.
- Confirm that CD player works.
- Listen to the CD
- Listen through the activity and understand where you will be using each of the materials.

HOW TO RUN THIS ACTIVITY

Facilitator

Tell participants we will now listen to the three stories from Activity 4 again but this time we should think about different ways to communicate with healthcare workers.

1. Nurse Olivia sees Youseff as he enters the Clinic. Youseff has been HIV positive for a few years now and comes to the health center frequently and he sits on the bench of the waiting room. He sees Nurse Olivia and greets her politely. He knows that Nurse Olivia always makes him wait until she has finished with all other patients in the waiting room, even those that arrived after he did. When it is finally Youseff's turn, she tells him that she is tired after a long day and she has little time for people like him, who are HIV positive.

2. Today is Wednesday and at the health center and it is ART Clinic day. There are already many people waiting. Dr. Obed is meeting with all the nurses from the Health Center to discuss important matters .This is the third time that Dr. Obed has called for a meetings with all the staff on Wednesday and has resulted in delayed consultations. Mary needs to talk with Nurse Fatima so she made an appointment

with her last week, but Nurse Fatima is still in the meeting and people are waiting. The ART consultation patients have to wait until Dr Obed finishes the meeting, already half past noon.

3. Esinam is not feeling well so she decides to go to the health center. She is HIV positive and recently started ART. She was taking the ART medication but she had severe headaches and nausea and decided to stop treatment, but she still is not feeling better. Today she goes to see Nurse Mary.

   When Nurse Mary finds out that Esinam has stopped the treatment, she gets upset and tells her in a very loud voice that she is not responsible and is very careless and that she is wasting ART treatment that could go to someone else who really wants it. Esinam really feels bad. She did now want to stop the treatment but the side effects are so strong.

Facilitator:
Tell participants that we will now discuss different ways to communicate with health providers.

Discussion on Communication Style of a Queen Mother/King:
Show the group the flashcards of the QUEEN MOTHER and the KING.
Ask for volunteers.

Ask the volunteers:

What are QUEEN MOTHERS and KINGS like and how do they behave in front of other people?

Possible Answers:
- Eye contact: Look people in the eye.
- Body language: Even without opening our mouths, our bodies can talk for us. Body language expreses how we feel about ourselves and what we are thinking. Our body language might influence how others will treat us.
  - Keep your shoulders squared and your chin up.
  - Act confident even if you don't feel it.
- Voice: Use a clear, calm voice. Make sure that your voice is loud enough to be heard. Try to be brief and concise in your language.
- Know what you want: Make sure you know what you would like out of the interaction. Know before you go into your meeting the type of information you would like to get. Don't be afraid to state your goals and ask questions. It's easier for people to give you what you want if they know what you want.

Facilitator:
Tell Participants the following:

If we behave like QUEEN MOTHERS and KINGS with health workers, it means we will confidently tell the health workers about our problems, ask the questions that we need to ask, and use our voices, our faces, and our body language in a way that makes people feel respect for us.

Tell participants that we will now start a role play:

- Divide the group into pairs.
- One person will play the patient role as the QUEEN MOTHER/KING and the other person will play the health worker role from one of the stories.
- Have the pair develop the role play about a PLHIV and a health provider.
- The role play should contain:
- The PLHIV patient asking key questions to the health worker.
- The health provider giving instruction to the patient on treatment.
- The PLHIV patient talking assertively to the health provider throughout the role play.
- After the first role play is done, then have the pair switch roles. Now the health worker is the patient.
- Have the pair develop a second role play based on a different story about a PLHIV and health providers.
- Encourage the pairs to give each other feedback.
- Visit each pair, observe the role plays, and give feedback when appropriate.

KEY POINTS:

PLHIV should act like Queen Mothers when they go to the health centers.

- They can communicate assertively with health workers regarding health decisions and issues

All PLHIV have the right to:

  - Be treated with dignity and respect, like any other patient.
  - Receive quality treatment and care.
  - Have our confidence kept and our privacy respected.
  - Be healthy and happy.

CREATIVE SCRIPT
****This information can also be found as an audio recording on the "My Life" CD (Disc 10)***

Module 9: Stigma And Discrimination
Activity 1: Stigma, Discrimination, And Your Life

SFX: Music up and down

Facilitator VO: Hello and welcome to the first activity of module 9. We will talk about stigma, which means shame or disgrace, and discrimination, which means unfair treatment, against people living with HIV. In this first activity, we will discuss the connection between stigma and discrimination and we will also seek to understand how stigma and discrimination affects you feel and think and how it affects the way you live your life.

When your moderator hears this bell….

FX: Bell rings

Facilitator VO: … that means it is time to stop the tape and begin discussions or an activity. When the discussion or activity is over, your moderator will push play to continue the activity.

This activity may generate a lot of questions. If possible, your moderator should try to invite a qualified health worker or a trained counselor to attend the meeting. If it's not possible, the moderator should keep track of the questions that he or she can't answer and try to find the answers for you before the next support group meeting.

Let's begin!

SFX: Music up and down

Facilitator VO: Let me start this activity by asking you a question: What are some examples of HIV stigma stigma is shame or disgrace that you have experienced? And what are some examples of HIV discrimination, which is unfair treatment that you or someone you know has experienced?

SFX: Bell rings

Facilitator VO: We have listed examples of stigma and discrimination we have experienced. Let me talk about a few examples with you.

Isolation is a form of stigma and discrimination. This means feeling alone. Being kicked out of your home would be a form of physical and social isolation from your family.

Violence is another form of discrimination. Violence can be physical, sexual or verbal towards people living with HIV or towards their friends and families.

Belittling, name-calling, blaming, or labeling people living with HIV as immoral is another form of stigma and discrimination.

Not being included in decisions related to the family or your own health because you are HIV-positive is another form of stigma and discrimination.

One more example of stigma and discrimination I would like to point out is being fired from your job. This is considered discrimination and it is not acceptable.

SFX: Music up and down

Facilitator VO: I'd like to ask another question: What do you think are some of the causes of HIV stigma and discrimination?

SFX: Bell rings

Facilitator VO: People discriminate and stigmatize people living with HIV because they lack the correct information and proper knowledge about HIV. And so they have incorrect ideas about how HIV is transmitted. These people may fear that they will get ill or die when they get close to a person living with HIV.

Another cause of discrimination and stigma in our communities are inequalities and prejudices that exist against certain groups of people.   For example women might be discriminated against because in our society they do not hold as much power as men. Or men who have sex with men and commercial sex workers might be discriminated against because our society labels them as "not good".

SFX: Music up and down

Facilitator VO: We will now listen to Edna's story about stigma and discrimination.

Remember we have already heard Edina's story in module 3 on Positive Living.

Edna's story will be divided into three parts so we can discuss important points throughout the story.
First, let's divide into small groups so that everyone has a chance to talk when we are answering questions.

At the end of the story, we will review the main points and discuss them with the larger group. So please break into small groups. After you have broken into small groups your facilitator will start the story.

SFX: Bell rings

Edna: When I was diagnosed as HIV positive about 8 years ago, I was shocked because I had been faithful to my husband for many years and the diagnosis meant that he had been having sex with other women while he was married to me. When I told him about the HIV test results he told me to leave…

SFX: background while Edna continues to talk man driving his wife away, children crying

… And he kept our two children.

Edna: So I left for my parents' house.

SFX: knock on door

Edna: But after talking to my parents about my situation, they also rejected me because they said they were afraid to get sick and also did not want anyone to know that their daughter was HIV positive. So I had to leave. I left the village and went to the city to try to find a job so I could feed myself

SFX: city sounds

Edna: It has not been easy. I slept outside on the pavement for many nights. And I often felt like I wanted to die because I didn't matter to anyone. I thought God must be punishing me for something I had done. In just a few minutes everything in my life changed. I had lost my right to a relationship, children, a job, to travel, to be happy---everything had changed but nothing had changed….

I felt like I was marked, different from everyone else. I felt dirty, ashamed and guiltyalthough I wasn't sure why I felt guilty. It is hard to convey the confused feelings about getting ready to die when I felt perfectly well.

An HIV diagnosis is life changing---it makes you feel dirty, abnormal, and frightened. My first challenge was to regain a sense of self-worth and to take back control over my life.

Facilitator VO: That was the first part of Edna's story. I have two questions I want you to discuss in your small groups: How did stigma and discrimination affect Edna? And how did it make her feel about herself?

SFX: Bell rings

Facilitator VO: I'm sure you were able to list many ways that stigma and discrimination affected Edna and how it caused her to feel bad about herself. I would like to talk about some of the negative feelings about themselves many people living with HIV have over the course of their lives. We all react differently so you may recognize some of these feelings or you may not.

Many people living with HIV have feelings of sadness, hatred towards themselves and others, revenge and may even feel that they want to infect other people so that others can be like them.

People living with HIV may become depressed and develop a low self-esteem. They may feel worthless and feel that they have nothing to live for. People living with HIV may feel like they have no power or control over their own lives. Self-stigma may make a person feel dirty, unclean and inferior to others and cause a person to blame themselves for all their troubles.

Often we will see people living with HIV end relationships with friends and families because they are afraid of being rejected if they are found to be HIV positive. Or they end relationships with family because people living with HIV fear causing their families any shame.

Some people will deny their test results and avoid practicing safe behaviors, like wearing a condom. They may not wear a condom because they fear this might tip off their partner that they are HIV-positive.

SFX: Music up and down

Facilitator VO: Now, we will listen in more detail to what happened when Edna told her husband and family she was HIV-positive. This time we will be looking to see how stigma and discrimination from other people affected Edna.

SFX: Music up and down

Edna: I did not want to keep secrets from my husband, Kofi, so I told him I was HIV-positive. At first he did not believe me. I had to actually show him the paper with the test results on it from the health center. Once he realized it was true he got very angry and blamed me for being HIV positive. He told me he no longer wanted me in the house because I could pass HIV onto my children.

I could not believe what I was hearing! I didn't think I could ever be separated from my children. I thought my husband would support me not hurt me more. I ran from the room because I was scared he would hit me.

SFX: night sounds of crickets and dogs

That night my family found out about the fight I had with my husband and they told me that I should leave the village. Then they told me that my children were better off without me. My mom said she would help Kofi take care of the children. I couldn't believe it! I told the truth and my life began falling apart. No one wanted to be around me. I felt like a monster. I had brought shame to my family. So I left the village.

SFX: Music up and down

Facilitator VO: Wow, Edna sure sounds like she is having a tough time. In our small groups, I would like you to discuss this question: What were the effects of people stigmatizing and discriminating against Edna? You can also share some of your own experiences and feelings with the group.

SFX: Bell rings

Facilitator VO: The following are some examples of stigmatization and discrimination;

- People think that others are dirty, unclean, or immoral because they are living with HIV.
- They blame people living with HIV for their disease.
- They think of people living with HIV as inferior to others because they are HIV Positive. They tend to isolate them physically, socially and emotionally.
- Others engage in acts of violence against people living with HIV.
- Close friends and family cut off familial, economic, and social support networks to people living with HIV.
- Some bosses even fire employees living with HIV.
- People avoid testing for HIV for fear of testing positive.
- Neighbors insult and gossip about others. They consider a person living with HIV as the "walking dead" or already dead, and not deserving of any love and respect.

SFX: Music up and down

Facilitator: Let's listen to the final part of Edna's story.

SFX: Music up and down

Edna: One day I was desperate so I went to a local church to seek help….

SFX: people singing at a church service

Edna: … At first people there did not want me to stay, but a kind man gave me food and helped me get a job at a fish factory nearby. I often asked God why he was punishing me in this way. One day I heard a voice inside me saying that I needed to do something to keep my job in the fish factory. I needed to accept what was happening to me and I needed to learn to live with it because no one else could do that for me; I had to do it by myself.

Over the next few years I realized that there were many people living with HIV and AIDS who were being rejected by their families and their communities. So I began to speak to people about my experience and offered help where I could….

SFX: muffled voice of woman speaking in the background

… I was determined to live and I believed that I had to do love positively first before I could change the way other people thought, and then I did not feel alone any more.

SFX: Music up and down

Facilitator VO: What helped Edna to help herself?

SFX: Bell rings

Facilitator VO: Let's summarize the things that helped Edna to help herself.

1. She found a resource that could help her the church or supportive persons
2. She found someone who accepted her as an HIV positive person
3. She disclosed her status and began to accept herself
4. She changed her attitude
5. She found a new purpose in her job

I believe some of us have sought help from other sources apart from those I have just mentioned. Please share your experiences with us and tell us how you feel about it.

SFX: Bell rings

Facilitator VO: Remember that there is a difference between stigma within yourself and stigma from others. The way we see ourselves may be different from how others see us.
Think about these points:

- The way we see yourself may be shaped by how others see us, including their prejudices.
- We have the power to accept the positive.
- We have the power to reject or change the negative.
- Only we have the power to change ourselves, others cannot change us.

SFX: Music up and down

Whenever you need additional help please use a cell phone to text “HELP” to 1406. This is the texting and helpline service for people living with HIV. A friendly counsellor will call you back within 24 hours to talk with you over the phone. This helpline is open everyday, except on Saturdays, Sundays and holidays.

I hope we will try to see the positive in ourselves from now on. See you at the next activity.

SFX: Music up and out.

Module 9: Stigma And Discrimination
Activity 2: Coping With Stigma And Discrimination

SFX: Music up and down

Facilitator VO: Hello and welcome to the second activity in module 9. This activity will help you come up with strategies to recognize stigma and discrimination in order for you to find ways to cope with them.

To do this, we will define what stigma and discrimination are. When you have identified them I believe it becomes easier to find ways to cope with them.

When your moderator hears this bell….

FX: Bell rings

Facilitator VO: … that means it is time to stop the tape and begin discussions or an activity. When the discussion or activity is over, your moderator will push play to continue the activity.

This activity may generate a lot of questions. If possible, your moderator should try to invite a qualified health worker or a trained counselor to attend the meeting. If it's not possible, the moderator should keep track of the questions that he or she can't answer and try to find the answers for you before the next support group meeting.

Let's begin!

SFX: Music up and down

Facilitator VO: I will now ask you to split into smaller groups to discuss the following question among yourselves. Afterwards we will come back together as one group and share what we have found. The question is: What is HIV Stigma and discrimination according to you?

SFX: Bell rings

Facilitator VO: Now let's come together and share the information we have from our own small groups.

SFX: Bell rings

Facilitator VO: Here are some key points we should always remember.

According to UNAIDS HIV and AIDS related stigma is believing or thinking that people living with HIV or associated with HIV are less valuable than other people

It is the belief that someone is inferior, or not a good person, because they have HIV. An example is the belief that People Living with HIV deserve what happened to them because they did something immoral or illegal.

HIV and AIDS discrimination is when someone treats or acts unfairly or unkindly towards someone because they either think or they know that they have HIV. For example, when people living with HIV lose their jobs or are refused treatment or are treated unfairly by health care providers

SFX: Music up and down

Facilitator VO: What are the possible sources of HIV and AIDS stigma and discrimination?

SFX: Bell rings

Facilitator VO: Thank you! Let's recap some of the sources of stigma and discrimination in our society:

- Lack of accurate information.
- People have wrong ideas and misunderstandings about HIV and the ways that HIV is passed from one person to another.
- People make assumptions based on these wrong ideas and misinformation.

Here are some examples of misconceptions:

- If a woman does not have children or is not married, there must be something wrong with her, or she is sick.
- If someone has lost weight or maybe looks tired it must be HIV.
- If a person has HIV, they must have done something to deserve it or they are a bad person.
- If I eat with someone with HIV I will get HIV too.

SFX: Music up and down

Facilitator VO: I believe that some of us have been through some stigma and discrimination and found a way to overcome it. Some of us may be going through something like that now. In your small groups please share your experiences of stigma and discrimination among yourselves. You can also think about and discuss what helped you get through those times and what people can do if they find themselves in such situations.

SFX: Bell rings

Facilitator VO: Let's come back together and share examples of how you coped with stigma and discrimination.

SFX: Bell rings

Facilitator VO: From our discussions we have realized that we can overcome people who stigmatize and discriminate by challenging them. We can cope with stigma by responding in a non -aggressive way. We will be able to overcome the situation if we do not make the person stigmatizing you feel defensive.

When it becomes obvious that someone is stigmatizing you, try to provide a strong response that makes the other person think. Some examples of strong responses are;

MVO: You are probably not aware that you are stigmatizing.
MVO: You only need to sleep with one person to get HIV.
MVO: All of us are at risk of getting HIV so there is no point stigmatizing others.
MVO: Anyone can get HIV, so put yourself in my shoes and think how you would feel.
MVO: The same thing could happen to you.
MVO: Don't point fingers at anyone. As you point one finger at another person, four fingers are pointing back at you.

We must try to correct wrong ideas that people have about HIV. We can do this and make ourselves feel better too by talking to friends or family about our experiences with stigma and discrimination. We can also extend a hand and provide support to our friends and family who are living with HIV and AIDS.
Most importantly, do not forget to take your anti-retroviral drugs and stick to the treatment to stay healthy.

SFX: Music up and down

Facilitator: Now let's practice responding to HIV Stigma and Discrimination. We will do a role play and come up with a method for coping with stigma and discrimination.

Form 3 groups now. Each group can select one of the following role plays to practise. Don't be afraid to get up onto your feet. Imagine you really are in the situation.

Role Play 1: You are going to the market and you pass close to a vendor. The vendor moves back to let you pass and tells you: "I do not want to get sick, do not come closer." How do you respond?

Role Play 2: You are at home and you hear your cousin say that she will not sit with you at the same table because she thinks that you are evil. How do you respond?

Role Play 3: You are talking to some friends and they say, "You have been talking a lot about AIDS and telling us to get tested. Does that mean you have AIDS? Have you been tested for AIDS?" How would you respond to your friends in this situation?

SFX: Bell rings

Facilitator VO: Let's come together and share our responses.

SFX: Bell rings

Facilitator VO: I hope you had fun doing this activity. Keep on practicing these very useful responses to stigma and discrimination.

Whenever you need additional help please use a cell phone to text “HELP” to 1406. This is the texting and helpline service for people living with HIV. A friendly counsellor will call you back within 24 hours to talk with you over the phone. This helpline is open everyday, except on Saturdays, Sundays and holidays.

See you in the next activity. We will be talking about how stigma and discrimination affects your health.

SFX: Music up and out.

Module 9: Stigma And Discrimination
Activity 3: Stigma, Discrimination And Your Health

SFX: Music up and down

Facilitator VO: Hello and welcome to activity 3 of module 9. We will be talking about how stigma and discrimination affects the physical and emotional health of people living with HIV and AIDS. This will help you to find ways of improving your health.

When your moderator hears this bell….

FX: Bell rings

Facilitator VO: … that means it is time to stop the tape and begin discussions or an activity. When the discussion or activity is over, your moderator will push play to continue the activity.

This activity may generate a lot of questions. If possible, your moderator should try to invite a qualified health worker or a trained counselor to attend the meeting. If it's not possible, the moderator should keep track of the questions that he or she can't answer and try to find the answers for you before the next support group meeting.

Let's begin!

SFX: Music up and down

Facilitator VO: I will start this activity by asking you to give me some examples of HIV related stigma and discrimination. Can you think of any?

SFX: Bell rings

Facilitator VO: From your answers we can sum up some key examples of stigma and discrimination. These are;

- Physical, sexual, or verbal violence towards people living with HIV or towards their family and friends.
- People living with HIV suffering from physical or social isolation from family and friends and sometimes getting kicked out of the house.
- People living with HIV not being included in decisions related to the family or one's own health and well-being.
- People living with HIV suffering belittling and name-calling, being blamed and being labeled as "immoral" for having HIV.
- People living with HIV being fired from their jobs.

SFX: Music up and down

Facilitator VO: Now let me ask you, How can HIV and AIDS related stigma and discrimination affect a person who is HIV positive?

SFX: Bell rings

Facilitator VO: Thank you for your ideas. We can see that stigma and discrimination can lower the way you feel about yourself. It creates the belief that you are going to die soon. Shame and unfair treatment increase stress levels, which can have a negative impact on your immune system. Stigma and discrimination can make you worry and feel negative, causing depression, which may cause you to stop eating and get sicker. Stigma and discrimination can make you feel isolated and powerless and, in some cases, useless.

SFX: Music up and down

Facilitator VO: As we all know, there is a link between the mind and body. For example, many people believe that physical health is affected by emotional health. Poor emotional health can result from experiences of stigma and discrimination.

Now we will listen to Lucy's story.

SFX: bags being thrown onto the ground and furniture being moved.

MVO: Look, you had better find a house close to the cemetery; we do not have any money to make arrangements for your funeral let alone your husband's.

Lucy: (sobbing) At 23 I was pregnant with my second child. I was caring for my ailing husband and our five-year old son with money I earned from my vegetable kiosk. But when word got out that my husband and I were living with HIV, my customers stopped coming, because they feared catching HIV.

SFX: market ambience (with voice of woman shouting "tomatoes, tomatoes… ")

Lucy: The situation took its toll on me. Soon after my baby was born I weighed only 45 kg. Then two months later my baby died from pneumonia. My world fell apart and I wanted to give up living so badly.

What stopped me was the hope that I saw radiating from my five-year-old son every day. Then one day I met Miriam, a church social worker.

SFX: footsteps and street ambience

Lucy: Hmmm. So that is my story. I am so lonely and longing for someone to talk to about my situation.

Miriam: Don't worry; I know a support group for people living with HIV that can help you get back on your feet. You can talk to them and they will understand what you are going through. They meet often at the church in the junction. I'll take you there so that you can get all the support you need to stay healthy for your child and your husband, OK.

Lucy: When I went for the first time to the HIV support group meeting Miriam introduced me to the group members. I decided to join the support group and I also started following the eating program that they offered for people living with HIV. I have now gained 10 kilos and my CD4 count has risen from 280 to 540.

And now I can retain the food I eat. Before I was always sickly and spent most of my time in bed. Now I sometimes get ill, but it's only once in a while, and my life has made a complete turnaround from last year.

I feel strong most days and I do not worry all the time. Now I can take better care of my husband and my child. I am so grateful to have a group of people in my support group to help take care of me. I have not given up hope that I can be strong again and help my family.

SFX: Music up and down

Facilitator VO: Now let's think of some examples of the effects of stigma and discrimination on Lucy's body and mind?

SFX: Bell rings

Facilitator VO: Let's summarize your responses

Many believe there is a connection between the mind and body. Studies have shown that stress, worrying, prolonged grief, depression, feeling bad about yourself, and negative thinking can impact the immune system and can weaken it. This makes your body weak and unable to fight off illnesses.

SFX: Music up and down

Facilitator VO: Now let's think about the effects of Lucy's positive attitudes on her body and mind? What were they?

SFX: Bell rings

Facilitator VO: Lets' recap everything we have learnt from Lucy's story;

- Positive thinking, support from loved ones, standing up for yourself, physical exercise, and reduced levels of stress and grief can have a positive impact on the immune system and health.
- Also, those who have disclosed their HIV status at least to some of their loved ones, are generally better able to get to the right health care services and social support networks.
- Joining a support group can boost your morale, and your immune system.
- Other things we can do to boost the immune system include:
  - Continuously take your medication according to the doctor's instructions.
  - Believe that you can live positively with HIV.
  - Believe that you have the right to be loved, respected, and to live life to it's fullest.

- Disclose your HIV status to trusted loved ones and talk about problems openly and honestly.
- Have life purpose and goals: research shows that people living with HIV who have remained healthy for long periods of time show that they have “reasons to live,” that are either general or specific. For example; “I want to enjoy my family and friends” or “I want to watch my children grow up” or “I want to take a class next month.”
- Stick up for yourself and your self-interests. This will help you feel better about yourself.

One important point to remember in order to stay in good health is to take good care of your body with good nutrition, exercise and regular sleep.

SFX: Music up and down

Facilitator VO: How does it feel to be part of this support group where you have care, respect and love from others? Now let's share some personal stories of stigma and discrimination and how they have affected your physical and emotional health.

SFX: Bell rings

Facilitator VO: Thank you for sharing. Please keep these key points in mind.

- Studies have shown that stress, worrying, prolonged grief, depression, feeling bad about yourself, and negative thinking can have a negative impact on the immune system and weaken it.
- A weakened immune system leads to more time spent being sick. Research shows people living with HIV who have remained healthy for long periods of time state that they have “reasons to live, like “I want to enjoy my family and friends” or “I want to watch my children grow up” or “I want to take a class next month”. Having a life purpose and goals can keep you healthy.
- Sticking up for yourself and your self-interests makes you feel better about yourself.
- And taking good care of your body with good nutrition, exercise and regular sleep is important to stay healthy.

SFX: Music up and down.

Facilitator VO: I can see that you have really enjoyed this activity.

Whenever you need additional help please use a cell phone to text “HELP” to 1406. This is the texting and helpline service for people living with HIV. A friendly counsellor will call you back within 24 hours to talk with you over the phone. This helpline is open everyday, except on Saturdays, Sundays and holidays.

We have one more before we finish module 9. Join me at the next activity where we will be talking about health worker and patient interaction. See you then.

SFX: Music up and out.

Module 9: Stigma And Discrimination
Activity 4: Health Worker-patient Role Play

SFX: Music up and down

Facilitator VO: Hello and welcome to the final activity in module 9. Here we are going to focus on health worker patient interaction.

Our objective will be to gain basic skills in communicating assertively with health workers.

When your moderator hears this bell….

FX: Bell rings

Facilitator VO: …that means it is time to stop the tape and begin discussions or an activity. When the discussion or activity is over, your moderator will push play to continue the activity.

This activity may generate a lot of questions. If possible, your moderator should try to invite a qualified health worker or a trained counselor to attend the meeting. If it's not possible, the moderator should keep track of the questions that he or she can't answer and try to find the answers for you before the next support group meeting.

Let's begin!

SFX: Music up and down

When you are living with HIV you can act like a Queen Mother when dealing with health providers, ask key questions and make sure you get the right answers. You know Queen Mothers talk with some confidence and when they do, they get the right response. That is what you must do. You do not have to be timid.

We will now listen to 3 stories and learn about the different ways in which we can communicate with health providers.

SFX: Music up and down

STORY 1.

SFX: hospital ambience (doors opening and closing, people talking and footsteps, lots of voices)

Nurse (rudely): Youseff, hmmm, you sit on the bench outside and wait until I am finished with all these people. Then I can attend to you.

Yousseff: Madam, I've been here for such a long time and you have been attending to others who came after I did even before me. Since I found out I had HIV a few years ago, this is what you have been doing to me…

Nurse: Papa, papa! You cannot come here and tell me what to do. Did I tell you to get yourself infected? As for me I do not have enough time for HIV positive people like you. I already have a long day. Excuse me…

Youssef: Oh… but madam, how could you?

SFX: Music up and down

Facilitator VO: That was our first story. Let's now listen to the second one.

STORY 2.

SFX: hospital ambience (doors opening and closing, people talking and footsteps, lots of voices)

FVO1: Eh, are they having this meeting again?
FVO2: Hmmm. They say the Doctor is meeting them.
FVO1: Dr. Obed always decides to have his meetings on ART clinic days.
MVO: But this is not fair at all. Look at the time it is already half past noon and none of us have been attended to.
FVO1: I even booked my appointment to meet the nurse today and now I have to wait until their meeting is over.

SFX: voices fade out

SFX: Music up and down

Facilitator VO: Sometimes it can be really tiring when it comes to seeking medical attention. Here is the last story.

SFX: Music up and down

STORY 3.

SFX: hospital ambience (doors opening and closing, people talking and footsteps, lots of voices)

Essinam: Good morning Aunty Mary

Nurse: Good morning. How are you feeling today?

Essinam: I'm not too good.

Nurse: But you are still taking the ART treatment, right?

Essinam: Yes, but I stopped because I was having some severe headache and nausea after taking the drugs and.…

Nurse: (shouting) What do you mean? When we have given you medicine to make you well you then go and decide yourself when to take it and when not to take it! And now you have come, saying that you are not feeling well. You are being very irresponsible and careless. You are wasting medicine that could be given to someone else who will make good use of it.

Essinam: It's not like I want to stop the treatment, but… you see the side effects after taking the drugs were just too strong for me to bear…

Nurse: But how can you decide of your own accord to stop taking the medicine that the doctor has given you? Are you a doctor? (sarcastically) Then why don't you treat yourself?

SFX: Music up and down

Facilitator VO: What have you learnt from these three stories?

SFX: Bell rings

Facilitator VO: You can see that not all health providers are polite and willing to listen to your side of the story. Let's now try to answer these questions; "What are QUEEN MOTHERS and KINGS like? How do they behave in front of other people?"

SFX: Bell rings

Facilitator VO: Here are some useful tips for communicating like a Queen Mother or King when talking with health providers.

- Eye contact: Look the person in the eye.
- Body language: Even without opening your mouth, your body can talk for you. Body language expresses how you feel about yourself and what you are thinking. Your body language influences how others will treat you.
    - Keep your shoulders square and your chin up.
    - Act confident even if you don't feel it.
- Voice: Use a clear, calm voice. Make sure that your voice is loud enough to be heard. Try to be brief and concise in your language.
- Know what you want: Make sure you know what you would like to get out of the meeting before hand. Don't be afraid to state your goals and ask questions. It's easier for people to give you what you want if they know what you want.

SFX: Music up and down

F**acilitator VO:** Behaving like QUEEN MOTHERS and KINGS with health workers means we will confidently tell the health workers about our problems, ask the questions that we need to ask, and use our voices, our faces, and our body language in a way that makes people respect us.

We will now do a role-play.

Pair yourselves up and let one person be the Queen Mother or King and the other person be the health provider.

Come up with a scenario about a person living with HIV in an interaction with a health provider.

The person living with HIV should put key questions to the health worker

The health provider will give the patient instructions on treatment

Throughout the interaction each person must talk in character, so either like a queen mother or king or health provider.

After the first role-play, you will switch positions and come up with another interaction between a Queen Mother or King and a health worker.

Be sure to give each other feed back after every role play.

SFX: Bell rings

Facilitator VO: People living with HIV should act like Queen Mothers and Kings whenever they interact with health providers or visit the health centre. This way, they will be treated with dignity and respect like any other patient.

Please bear in mind that every person living with HIV has the right to be treated with respect, the right to receive quality treatment and care, the right to confidentiality and privacy and, above all the right to be healthy and happy.

Whenever you need additional help please use a cell phone to text “HELP” to 1406. This is the texting and helpline service for people living with HIV. A friendly counsellor will call you back within 24 hours to talk with you over the phone. This helpline is open everyday, except on Saturdays, Sundays and holidays.

See you at the next module.

SFX: Music up and out